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AUTHOR Wright, Barbara
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ABSTRACT

This publication provides background information on financing and programming for persons with developmental disabilities to assist state legislators in making public policy and funding decisions. The booklet is in a question-and-answer format and covers the following topics: (1) definition of developmental disabilities and factors of concern to legislators, including discussion of demographic changes, federal reforms, pressure to make the most efficient use of funds, and pressure from advocacy groups; (2) services needed by persons with developmental disabilities, in the areas of health care, home-based and community-based services, housing, jobs, income support, and education; (3) available federal, state, and local support and funding sources; (4) public and private support, including employer-mandated insurance coverage, high-risk pools, subsidies for private health insurance, and state-financed or state-mandated catastrophic health insurance; (5) state compliance with the Omnibus Budget Reconciliation Act, which requires states to find alternative placements for persons with mental handicaps who have been placed inappropriately in nursing homes; and (6) innovative state programs in the areas of family support services, housing, integrated education, supported employment, and transition programs. The guide includes 84 reference notes, a glossary, a list of acronyms, and a list of 15 organizational resources. (JDD)

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WHAT LEGISLATORS NEED TO KNOW ABOUT MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

Health Services Program

National Conference of State Legislatures

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National Conference of State Legislatures
1560 Broadway • Suite 700
Denver, Colorado 80202
(303) 830-2200
Fax (303) 863-8003

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- To foster interstate communication and cooperation; and
- To ensure states a strong, cohesive voice in the federal system.

The Conference operates from offices in Denver, Colorado, and Washington, D.C.

President:	Representative Lee A. Daniels, House Minority Leader, Illinois
Staff Chair:	Patrick J. O'Donnell, Clerk of the Legislature, Nebraska
Executive Director:	William T. Pound

WHAT LEGISLATORS NEED TO KNOW ABOUT MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

by

Barbara Wright

National Conference of State Legislatures

1560 Broadway, Suite 700
Denver, CO 80202-5140
(303) 830-2200 FAX (303) 863-8003

444 North Capitol Street, N.W., Suite 500
Washington, D.C. 20001

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This publication serves as a starting point for the newly created NCSL Task Force on Developmental Disabilities. The task force will issue a report in late 1990, which includes a compilation of state laws and recommendations for state legislative activity in the area of mental retardation and developmental disabilities.

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INTRODUCTION

Nearly four million Americans have a developmental disability such as mental retardation, epilepsy, cerebral palsy, or autism according to the U.S. Department of Health and Human Services.[1] In 1988, federal, state, and local governments spent $11.7 billion to care for persons with developmental disabilities.[2]

The number of persons residing in state-operated institutional facilities for persons with developmental disabilities declined from 149,169 in 1977, to 91,440 in 1988, a 39 percent drop.[3] Today, many people previously thought to require institutional care now live in small, supervised community residences, take public transportation to sheltered or supported jobs, participate in community recreation activities, receive social services where needed, and lead integrated lives in the community. Several states across the country are serving persons with developmental disabilities cost-effectively with innovative programs that focus on the needs of each individual and the natural supports available in most communities rather than on diagnostic labels and institutional placement.

However, much work remains for state legislators. Families in many states do not have the financial and support services to allow them to keep their child with a disability at home. People graduating or exiting from special education programs have trouble finding community programs or face long waiting lists. Residential options are limited in most states. While federal support is available, complicated bureaucratic regulations often restrict accessibility.

Legislators are under increasing pressure from consumers, families, advocates, and various officials to provide a range of services for persons with developmental disabilities. State budgets, however, are under siege. Many worthy causes compete for limited dollars and legislators face tough choices. They want to make sure that the programs they support are cost-effective.

This publication attempts to provide important background information on financing and programming for persons with developmental disabilities so legislators can make educated public policy and funding decisions in their states. The booklet is in a question-and-answer format and is organized as follows:

- The first two questions define developmental disabilities and present factors of concern to legislators, including discussion of demographic changes, federal reforms, pressure to make the most efficient use of funds, and pressure from advocacy groups.

- Question Three outlines what services persons with developmental disabilities need in the areas of health care, home- and community-based services, housing, jobs, income support, and education. Question Four reviews available federal, state, and local support in these same areas, and Question Five covers state and local funding sources.

- Question Six deals with public-private support that might be used to assist persons with developmental disabilities, including employer-mandated insurance coverage, high-risk pools, subsidies for private health insurance, and state-financed or state-mandated catastrophic health insurance.

- Question Seven describes state compliance with the Omnibus Budget Reconciliation Act (OBRA-87), which requires states to find alternative placements for persons with mental handicaps who have been placed inappropriately in nursing homes.

- Question Eight presents innovative state programs in the areas of family support services, housing, integrated education, supported employment, and transition programs.

QUESTION ONE: WHAT ARE MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES?

A *developmental disability* is a severe, disabling condition that arises in infancy or childhood; persists indefinitely; and causes serious problems in language, learning, mobility, and capacity for independent living. These disabilities often result from damage to the brain structure or functioning, such as epilepsy, cerebral palsy, multiple sclerosis, or autism.

Epilepsy is a disorder of the nervous system, characterized either by mild, episodic loss of attention or sleepiness (petit mal seizure) or by severe convulsions with loss of consciousness (grand mal seizure). *Cerebral palsy* is a form of paralysis believed to be caused by a prenatal brain defect or by brain injury during birth, most marked in certain motor areas characterized by difficulty in control of the voluntary muscles. *Multiple sclerosis* is a chronic degenerative, often episodic disease of the central nervous system, manifested by one or more mild to severe neural and muscular impairments, such as spastic weakness in one or more limbs or local sensory loss. *Autism* is a developmental disorder of children, characterized by impaired communication, excessive rigidity, and emotional detachment.

Mental retardation also is classified as a developmental disability. Persons with mental retardation mature at a below-average rate and have IQs of 70 or below. Increasingly, the relevance of IQ scores alone has come into question so professionals are relying on other aspects of a person's capabilities to determine if he or she has mental retardation. Approximately 2.5 percent of the population have an IQ below 70, but at any given time only about 1 percent is considered retarded. This is because a person is not diagnosed as retarded, even with an IQ below 70, unless social and personal functioning is so seriously deficient that special protection and services are needed. The four levels of retardation are mild, moderate, severe, and profound.[4]

- *Mild*. People with mild retardation constitute 80 percent of all persons with mental retardation. These people are, in many respects, similar to people without retardation and are not usually identified as retarded until they enter public school. They differ primarily in rate and degree of intellectual development. Persons with mild retardation are not considered developmentally disabled unless they have a secondary handicap.

- *Moderate*. People with moderate retardation (10-15 percent of all persons with mental retardation) can learn to speak in sentences, but have difficulty conforming to social conventions. They are unlikely to pass the second grade level and require supervision as adults.

- *Severe*. Accounting for 7 percent of all persons with retardation, those with severe retardation are able to learn some speech and elementary hygiene.

- *Profound*. People with profound retardation (1 percent of persons with mental retardation) have limited sensory awareness and mobility and need constant supervision.

The causes of mental retardation are poorly understood. In three out of four cases, its origin is unknown. Some of the most common causes of mental retardation include genetic irregularities, such as Down's syndrome or PKU (phenylketonuria); problems during pregnancy, such as those associated with drug or alcohol abuse, German measles, or other diseases; low birthweight; head injuries or childhood diseases that damage the brain; and malnutrition.[5]

Increasingly, states are adopting the federal definition of developmental disabilities based on functional abilities rather than diagnosis. A person with developmental disabilities must have substantial difficulties in three of the following areas: self-care, understanding and use of language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Under

the federal definition, a person with cerebral palsy, for instance, is not developmentally disabled unless the chronic condition affects major areas of his or her life.

QUESTION TWO: WHY SHOULD LEGISLATORS BE CONCERNED ABOUT PERSONS WITH DEVELOPMENTAL DISABILITIES?

Legislators should be concerned because millions of families seek affordable, quality services for their family members with handicaps. State governments spend more than $7.4 billion each year to provide services for persons with developmental disabilities.[6] In a time of strained state budgets, legislators are realizing the need to get the best and most efficient care and services for the money. In the future, legislators will face further pressures to design rational, cost-effective, and high-quality systems of care. Those pressures will be fueled by demographic changes, federal reforms, pressure to make the most efficient use of funds, pressure from advocacy groups, and increasing litigation.

Demographic changes. The baby boom generation includes one-half million retarded adults 25 to 44 years old whose parents will soon reach retirement age.[7] In Illinois, estimates range from 3,300 to 14,000 for the number of persons with developmental disabilities who are 30 years old and older, live with their families, and will require residential alternatives in the next 15 years.[8] In most states, persons with handicaps living with aging parents will place strong demands on service systems in the next decade.

In addition, many more low-birthweight babies survive today, thanks to new medical technology. Approximately 16 percent of the babies who weigh less than 3.3 pounds are born with moderate to severe disabilities that result from the infants' being too small. These babies will require costly medical and social services.[9] Researchers and clinicians also are expressing alarm at the sharp increase in drug-affected newborns in the last two years. Of the 56 million American women of childbearing age, an estimated eight million use at least one of the four major drugs (cocaine, alcohol, marijuana, and nicotine), and 15 percent or 1.2 million use the drugs in quantities sufficient to produce birth defects, including developmental disabilities.[10]

Other demographic changes, including increasing numbers of working mothers, more single-parent families, and smaller family size, indicate that families no longer may have the resources once available to them to care for children with handicaps without assistance.

Already, service systems are strained and many states' systems are experiencing long waiting lists for their services. Nationwide, consumer advocacy groups indicate that more than 60,000 persons with mental retardation who live with their families are waiting for placement in supervised residences and more than 75,000 are waiting for employment opportunities, day care, and counseling for them and their families.[11] Legislators are faced with the problems of both present and future need for services.

Federal reforms. Reforms at the federal level potentially will require states to revamp totally the way care for persons with developmental disabilities is financed and delivered. These include:

- *Medicaid reform*. At present, states may receive federal Medicaid funds for institutional care through the Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) Program. In FY 1988, $2.39 billion of federal matching money went to states for institutional care and $451 million of federal ICFs/MR funds went to other large private facilities. In that same year, only $252 million of Medicaid funds went to states for home- and community-based waiver services.[12] In the winter of 1990, Congress will consider legislation that would eliminate the Medicaid bias toward institutional care and direct more dollars toward home- and community-based services. The Senate's C..afee-Mitchell-

Dole Bill (S. 384) has 54 sponsors. The House's Florio-Waxman-Dingell Bill (H.R. 854) will be reintroduced in the House in 1990. While the final shape of the legislation is uncertain, most people agree that some version of Medicaid reform will become law and change the way states fund services for persons with disabilities.

- *Nursing home reform*. The Omnibus Budget Reconciliation Act of 1987 (OBRA-87) requires states to review the needs of all nursing home residents with a mental illness or developmental disability. States then must transfer all persons who are inappropriately placed if they have resided in a nursing facility for fewer than 30 months. States are confronted with funding placements for large numbers of persons with disabilities whose care was reimbursed by Medicaid when they lived in nursing homes. In addition, states must provide appropriate services for individuals who have resided in nursing homes for more than 30 months and choose to stay. Question Six deals with how states are complying with nursing home reform.

- *Americans with Disabilities Act*. This pending civil rights legislation would create sweeping rights protection in employment, government services, transportation, and public accommodation for all people with disabilities. The Senate version (S. 933) passed in 1989 and similar legislation is expected to pass in the U.S. House of Representatives in the spring of 1990.

In this time of transition, service systems need the leadership of state legislators to adapt to the changing environment.

Pressure to use funds efficiently. Cost-conscious legislators want to support programs that offer the most effective service for the least amount of money. For historical reasons, in many states this has not happened. States are trapped into using scarce dollars to match federal funds for expensive and often inappropriate institutional care, even though 90 percent of persons with disabilities live in the community.[13] In 1988, state and local governments spent $4.2 billion on community care and $2.7 billion on institutional care.[14] In other words, states spent close to 40 percent of their resources on 10 percent of their clients.

Policy in many states actually encourages institutional placement because sufficient family support services are not available and because reimbursement will pay for institutional care, but not home care. Medicaid reform aims to reverse this institutional bias. States also may work to use dollars more effectively by creating family and community programs to prevent expensive institutional alternatives.

Most professionals and advocates agree that the vast majority of children with developmental disabilities are better off in families where they form lifetime bonds, become integrated into the community, and lead richer and more productive lives. Home care is also less expensive than institutional care. A study by the Syracuse University Center on Human Policy evaluated the costs of serving severely handicapped children with institutional histories who are currently living with families. The study found that, on average, the cost of care for children in families was one-fourth to one-fifth that of institutional care.[15]

The 1988 average per diem rate for an institution for persons with developmental disabilities was $153.54, or $56,042 per year. Although state matching rates vary, the average state rate is 45 percent, or $25,219, to support one person in an institution each year.[16] In contrast, the average annual family subsidy payment in the United States was $2,567 in 1988.[17] The nation's largest cash subsidy program in Michigan, where institutional placements have declined 81 percent in the last 10 years, offers families $2,700 per year.[18] The average state's match for institutional care for one person could be given to 10 families to keep their children with handicaps at home.

Pressure from advocacy groups. Today, one out of every 10 Americans has a person with mental retardation in his or her extended family.[19] Parents have become increasingly articulate about the needs of their children with handicaps and aware of their potential if given the appropriate support. Since the passage of the Education for All Handicapped Children Act in 1975, a whole generation of children has benefitted from special education, and parents have seen the potential for their children to grow and change and lead productive lives. In the past two to three years, schools are graduating students with handicaps who have spent their entire school years receiving special education services and are now waiting for community services to replace the structure of school. Politically astute parents are forming coalitions in state after state. Increasingly, legislators are confronted with parents who have a clear vision of their children's needs.

Increasing litigation. More and more, litigation is being used as an agent for social change. Between 1971 and 1981, there were approximately 38 pending or completed class action right-to-habilitation suits in 27 states.[20] Habilitation services help ensure that persons with disabilities can function in daily living activities. Such services include health, social services, and assistive technology and devices.

At present, at least 21 states have lawsuits in progress or face court orders demanding state governments to enforce existing laws. Some laws require services for all people with disabilities, while others apply to persons with mental disabilities, a category that includes people with mental illness or mental retardation.[21] Mental retardation advocacy groups often are the moving parties or plaintiffs in key litigation.[22]

In a case that is generating national attention, the city of Philadelphia sued the state of Pennsylvania in 1989 for $7 million to restore services for adults with mental retardation who live at home. At issue is whether they have the same rights to care as those living in institutions or community homes.[23]

QUESTION THREE: WHAT KINDS OF SERVICES DO PERSONS WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES NEED?

A range of services is needed to respond effectively to the needs of persons with developmental disabilities and their families at various times in their lives. These services include health care, home- and community-based support services, housing, job training and placement, income support, and education. This diversity of service needs is a direct outgrowth of the wide-ranging differences in the nature and extent of the disabilities represented among persons with developmental disabilities. For example, there is little comparison between a set of services for a young adult with borderline retardation and the services needed by a person of similar age with profound retardation, multiple physical impairments, and chronic medical complications. Persons with developmental disabilities do not require one prescribed set of services, but rather the availability of a range of services that can meet individual needs.

Health Care

Many persons with mental retardation also have additional medical problems such as seizure disorders. Persons with mental retardation, cerebral palsy, epilepsy, and other developmental disabilities need access to affordable, quality health care in three areas:

- General medical services for routine health maintenance;

- Emergency health and mental health services for crisis medical and psychiatric episodes; and

- Hospitals, for acute medical problems.

In addition, individuals with seizure disorders need specific ongoing care for seizure management and side effects of anticonvulsant medication. Individuals with cerebral palsy may need special orthopedic services, surgeries, appliances such as braces or crutches, and long-term management of the effects of spastic muscles. A small percentage of children with developmental disabilities have complex medical needs that require regular intervention from a variety of medical specialists.

Home- and Community-Based Support Services

All national studies on deinstitutionalization of persons with developmental disabilities support the premise that persons with disabilities who are served at home or in community settings make more progress toward leading integrated, independent lives than those who live in institutions. Depending on the type and severity of the disability, persons with handicaps living outside institutions need varying services. These include family support services to help families maintain their child with a disability at home and consumer support services that may be necessary whether the person with a disability is living at home or in a community setting.

Family support services. Families who care for a child with a serious handicap live day to day with special needs that most families never have to consider. Children with disabilities often require round-the-clock care and supervision. Extra expenses include specialized equipment, such as wheelchairs, communication devices, adult-sized diapers, and vans with lift devices. Home modifications such as accessible bathrooms and ramps often are necessary.

Many states have created family support programs to help the child stay with his or her parents and to avoid expensive institutional alternatives. Exemplary family support programs provide services that enable families to make informed decisions, are responsive to the needs of the entire family unit, and are flexible enough to accommodate each family's needs. Components of family support programs include the following:

- *Family subsidies*. Families receive support, either through a cash payment or voucher system, to help defray the costs of caring for a child with a disability. At least 20 states have initiated cash assistance programs, although most are modest in scope.[24] In these programs, families either receive a periodic subsidy or stipend and pay the support agents of their choice, or are reimbursed for the costs that are incurred. Restrictions may be placed on the types of expenses to which the cash may be applied, and family members may need to show receipts to document how the cash was spent.

- *Respite care*. This service offers families temporary relief or a "vacation" from caring for their disabled child. Respite care can be provided by family sitters who care for the child in the home for a few hours or a day. Temporary residences provide care for longer periods, usually up to 30 days.

- *Attendant care*. Paid employees come to the home to help persons with severe disabilities bathe, dress, eat, or do other activities.

- *Home health aides/visiting nurses*. Trained professionals offer services to housebound persons in need of home health care.

- *Family education and support groups*. Family caretakers receive instruction in developmental expectations, behavior analysis, health maintenance, consumer education, legal rights, and advocacy. In self-help and support groups, families with children who have developmental disabilities provide each other with emotional support and practical help with problems.

- *Marital and family counseling*. Families receive help with problems stemming from the strain of constantly caring for a person with a serious disability.

- *Crisis management*. A family may need to transfer its child temporarily to a respite home, specialized mental health facility, or other alternative care center during times of acute need. Psychologists, behavior specialists, or psychiatrists provide the family with guidance to cope with the problem behavior once the child returns home.

- *Family-centered case management*. Case managers or service coordinators visit the home and assist the family with information about the nature of its child's disability and appropriate services and support in the community in order to put together the array of services needed to keep the child at home.

Consumer support services. Persons with mental retardation and/or physical impairments require assistance to be able to live in the community. Examples of consumer support services include the following:

- *Early intervention*. Infants, toddlers, and preschoolers need specialized services to stimulate motor activity, learning, and social skills. Research demonstrates that an investment in prompt, early intervention results in reduced expenditures for special education and related services in later years.

- *Behavior management*. Working with therapists or qualified professionals, consumers learn to replace antisocial or self-destructive behaviors with safer or more appropriate behaviors.

- *Physical therapy*. Some disabilities require extensive physical therapy to maintain or increase the use of neuromuscular, skeletal, cardiovascular, and respiratory systems. For children with cerebral palsy and other neuromuscular conditions, appropriate seating and positioning to relieve stress on the muscular system are essential before the provision of other services.

- *Communication and language therapy*. Depending on the disability, therapy may be necessary to eliminate speech defects, develop or improve speaking intelligibility, or learn sign language. Augmentative communication devices are needed by individuals whose disability precludes functional speech.

- *Transportation*. Persons with disabilities need transportation to and from their residence and/or between various service delivery sites, such as jobs, schools, day programs, health centers, and recreation sites.

- *Personal attendant services*. Youth and adults unable to manage their own self-care needs can live more independently in their own homes with personal attendant services for specified portions of the day.

- *Case management or service coordination*. A case manager or service coordinator is the human link between the consumer and the service agencies and serves as a guide through the complex array of programs, thus making services more accessible. The case manager may be responsible for assessing the consumer's needs, helping develop a comprehensive

service plan, advocating on behalf of consumers, matching the consumer with various service providers, and linking service providers with one another to assure that services are well-coordinated and provided in a timely manner.

Housing

States are moving away from housing persons with mental or physical handicaps in large, congregate care facilities and moving toward small, community-based residential options with supportive services. A spectrum of residential arrangements includes the following:

Supported living. Residents live in their own apartments or small homes and receive support as needed from staff who are nearby or on-call. This approach recognizes the need for a person with developmental disabilities to have his or her own home with roommates of personal choice, and, with the necessary supports, to function as independently as possible in that home. Apartments may be leased either in the name of the resident or by the supportive agency, which in turn collects rent from the tenants.

Family care homes. Private home owners are paid to provide lodging, meals, and clothing for one to six persons with disabilities in their own homes. The "surrogate parents" are reimbursed for medical, dental, and other expenses necessary to provide a home for the residents. In contrast to boarding homes, family care homes offer greater supervision and training and a more home-like environment.

Boarding homes. Private home owners rent rooms to one or more residents within their homes. Meals, some housekeeping, and a watchful eye are provided, but not formal supervision or training.

Intermediate care facilities for the mentally retarded. These public or private facilities provide 24-hour care to persons with developmental disabilities and stabilized health problems. A facility must be certified as an ICF/MR to receive Medicaid reimbursement.

Group homes. These facilities of up to 15 beds have similar resident and staffing levels as ICFs/MR, but are not certified to receive Medicaid reimbursement.

Job Training and Placement

Training and employing persons with disabilities increase their integration into the community and decrease their reliance on public funds. Assumptions about what constitutes good vocational programming are changing. Increasingly, professionals are stressing newer approaches, such as supported employment, which are oriented to putting people in competitive employment. The following programs help persons with disabilities enter the job market:

Supported employment. Individuals are assessed to determine their capabilities and interests, assisted in finding an appropriate job, placed in the job, and supported in a variety of ways such as job site adaption, job redesign, training, and transportation. Job coaches are provided to individuals who work in paid jobs in a variety of settings, particularly work sites where individuals with handicaps work side by side with nonhandicapped workers. Support is provided through activities such as training, supervision, and transportation. Workers with disabilities sometimes are employed directly through the business or may remain employees of the nonprofit organization providing ongoing support.

Supported employment programs in most states have been initiated only in the last five years. However, they rapidly are becoming the program of choice because supported employment advances the goal of integrating persons with serious handicaps in the community through employment. In

addition, clients earn money, pay taxes, lessen their dependence on public support programs, and increase their self-esteem.

Transition programs. These programs are targeted at young adults who graduate or exit from public school and need help to make the transition to adult and working life. Exemplary programs are finding that the best practice is to begin transitional planning between the ages of 14 and 16. In addition to specific job training and placement, these programs help consumers manage money, travel to and from work independently, and interact socially with other individuals.

Sheltered employment. These programs primarily serve persons with disabilities. The workshop subcontracts with a local business or industry for jobs. Staff members evaluate clients, offer training, and supervise them on the job. When clients are deemed work-ready, they are placed in a competitive job or supported employment. Workers in sheltered workshops are paid wages according to their productivity levels.

Work activity programs. These programs help clients acquire work-related skills and produce usable products and services.

Adult day programs. Clients in a group setting receive instruction in daily living skills, treatment for maladaptive behavior, and work orientation training.

Income Support

Social Security provides income support to persons with developmental disabilities through three different channels: Supplemental Security Income (SSI), Adult Disabled Child (ADC) benefits, and Social Security Disability Insurance (SSDI). SSI provides monthly cash payments to individuals who are below specified levels. These monthly payments are supplemented by some states. Adult Disabled Child benefits are provided to adult children with developmental disabilities who have a retired, disabled, or deceased parent who has earned coverage through Social Security.

SSDI provides payments to persons who have paid into the Social Security system through their employment and who no longer can work because of a severe disability. Unlike SSI eligibility, which is based on income, SSDI eligibility is based on employment history. SSDI recipients receive an additional monthly allotment for each child, including children with disabilities, up to a family maximum.

Education

The Education for All Handicapped Children Act is intended to guarantee each child the right to an appropriate education in the least restrictive environment. An estimated 4.3 million children receive education services because of a handicap or disability.[25] Local school districts may choose to serve these children in several educational settings, including regular classrooms, separate classrooms, or separate schools. About 1 percent of children with disabilities require other teaching environments, such as hospitals or convalescent homes.[26] Special education children cover a wide spectrum of disabilities, from the approximately 43 percent who have mild learning disabilities to a relatively small number of children with severe handicaps.[27]

Increasingly, parents of children with handicaps are interpreting the mandate for "mainstreaming" to mean placing children with handicaps in regular classrooms with their peers. Programs available through the public schools are divided into the following categories:

- *Early intervention services (ages zero through two years).* These services aim to help children with handicaps catch up to other children their age and diminish the need for specialized services later in life.

- *Preschool services (ages three through five).* Preschool instruction typically may cover motor development, communication, socialization, self-help, and cognitive development.

- *Special education services (school-aged children).* Tailored to the child's disability, these services focus on teaching age-appropriate skills. As the child grows older, instruction focuses increasingly on developing community life and vocational skills.

QUESTION FOUR: WHAT FEDERAL ASSISTANCE IS AVAILABLE?

Significant federal money is available to support persons with developmental disabilities. With careful planning, states can put together a system to make the most of federal support and stretch state dollars. The federal programs listed here are divided into categories of health care, home- and community-based services, housing, job training and placement, income support, and education.

Health Care

Medicaid. Medicaid is a federally matched, state-run medical assistance program for eligible low-income persons. The program often is referred to as Title XIX because of its authorizing legislation. The federal government establishes guidelines for the program and pays a portion of each state's medical assistance payments, ranging from a low of 50 percent to a high of 80 percent (see Table 1).

The federal government requires that certain groups be served under Medicaid, including recipients of Supplemental Security Income, subject to state restrictions, and Aid to Families with Dependent Children (AFDC). Some other categories of persons are eligible for Medicaid at the state's option.

For persons under 18 years of age with handicaps, parental income is counted as a resource available to the child. This situation creates severe hardship for many families who want to care for their children at home, but whose income makes them ineligible for Medicaid coverage. In fact, the policy actually encourages out-of-home placement.

States may elect to offer Medicaid services to children living at home without considering family income by modifying the state's Medicaid plan in accordance with the Tax Equity and Fiscal Responsibility Act (TEFRA) passed in 1982 (Section 134 of P.L. 97-35). The TEFRA coverage option has been elected by 19 states. Many of these states, however, apply it to a very narrow range of potential beneficiaries.[28]

Recent changes in Medicaid coverage that affect persons with disabilities include the following:[29]

- *COBRA-85.* The Consolidated Omnibus Budget Reconciliation Act of 1985 allows states to offer case management as an optional Medicaid-funded service.

- *OBRA-86.* The Omnibus Budget Reconciliation Act of 1986 authorizes state Medicaid coverage of at-home respiratory care services for ventilator-dependent individuals.

- *OBRA-87.* The Omnibus Budget Reconciliation Act of 1987 requires nursing homes that receive federal funds to place residents with disabilities who do not require 24-hour nursing in less restrictive settings. Question Seven addresses this issue.

- *Medicaid Technical Amendment of 1988 within P.L. 100-146.* States have the option to include special education-related services under P.L. 94-142 and early intervention and family support services under P.L. 99-457 in their state Medicaid plan in order to receive federal matching funds. These two federal laws are described in this question under "Education."

Table 1.

Federal Medicaid Matching Rate for Medical Assistance by State (FY 1990)

State	Rate	State	Rate
Alabama	73.21	Nebraska	61.12
Alaska	50.00	Nevada	50.00
Arizona	60.99	New Hampshire	50.00
Arkansas	74.58	New Jersey	50.00
California	50.00	New Mexico	72.25
Colorado	52.11	New York	50.00
Connecticut	50.00	North Carolina	67.46
Delaware	50.00	North Dakota	67.52
Florida	54.70	Ohio	59.57
Georgia	62.09	Oklahoma	68.29
Hawaii	54.50	Oregon	62.95
Idaho	73.32	Pennsylvania	56.86
Illinois	50.00	Rhode Island	55.15
Indiana	63.76	South Carolina	73.07
Iowa	62.52	South Dakota	70.90
Kansas	56.07	Tennessee	69.64
Kentucky	72.95	Texas	61.23
Louisiana	73.12	Utah	74.70
Maine	65.20	Vermont	62.77
Maryland	50.00	Virginia	50.00
Massachusetts	50.00	Washington	53.88
Michigan	54.54	West Virginia	76.61
Minnesota	52.74	Wisconsin	59.28
Missippippi	80.18	Wyoming	65.95
Missouri	59.18	District of Columbia	50.00
Montana	71.35	Puerto Rico	50.00

Source: U.S. Department of Health and Human Services, December 1989.

Medicare. Medicare is a federal health insurance program covering services to persons aged 65 and above, and to adults under age 65 and their offspring who have been receiving Social Security Disability Insurance benefits or Adult Disabled Child benefits for at least 24 months.

Maternal and Child Health block grant. This block grant enables states to develop or enhance systems to assure that children with special medical needs have access to primary health care services. States are given wide latitude over structure, target populations, and services. Every four federal dollars must be matched with three state dollars. Roughly 15 percent of the congressional appropriation for this block grant goes to fund discretionary grants referred to as Special Projects of Regional and National Significance (SPRANS).[30]

Technology Assistance Act (P.L. 100-407). This 1988 act is an effort by federal lawmakers to stimulate effective use of modern technology on behalf of all 43 million persons with disabling conditions, including the four million persons with developmental disabilities. States may apply to the secretary of the Department of Education for three-year grants of $50,000 per year to provide training and assistance and to establish model consumer-responsive service delivery systems to help individuals with disabilities use technology or devices.

Home- and Community-Based Services

Medicaid Home- and Community-Based Services Program (or the "2176 waiver"). Although originally intended to provide only medical services, Medicaid dollars may be used for a variety of nonmedical home- and community-based support services for recipients who otherwise would need more costly institutional care through the Home- and Community-Based Services Program. This program was authorized under Section 2176 of the Omnibus Budget Reconciliation Act of 1981. Federal support for 2176 waivers grew from $1.25 million in FY 1983 to $248 million in FY 1988.[31] As of 1988, 36 states offered services to 29,087 clients through this program.[32]

Medicaid's Model Waiver Option. Similar in purpose to that of the home- and community-based waivers, the model waiver allows Medicaid coverage of home care for individuals who otherwise would be served in an institutional setting at an equal or higher cost. Most participating states use the model waiver option to support home care for small numbers of targeted subpopulations, such as ventilator-dependent children living at home. These waivers sometimes are referred to as Model 50 waivers, Model 50/200 waivers, or Katie Beckett waivers. In many states, narrow eligibility criteria, complex application procedures, and poorly advertised availability prevent people from applying.[33]

Developmental Disabilities Act (P.L. 100-146). Reauthorized in 1987, this federal act aims to enable persons with developmental disabilities to achieve their maximum potential through three key concepts, which have become goals for many programs serving this population nationwide: independence, productivity, and integration into the community. The act provides grants for services such as case management, community living, and advocacy for persons with developmental disabilities. Most important, the act requires states to establish a Developmental Disabilities Council and to give the council planning authority to address the needs of persons with developmental disabilities. The act also requires each state to establish a protection and advocacy system funded by a separate line item to ensure legal rights for persons with developmental disabilities. States must devote 65 percent of the federal grant to federal priority areas, such as family support services, to strengthen the role of families as primary caregivers.

Crisis nurseries and respite care. An extension of the Temporary Child Care for Handicapped Children and Crisis Nursery Act of 1986 (P.L. 100-403), this program makes federal grants to states to fund agencies and organizations that provide respite care services for children with handicaps and nurseries for children in crisis because of abuse or neglect. Congress appropriated $5 million for this

program in FY 1989. The program has the potential to become a more significant source of support for children with handicaps in the future.[34]

Other federal programs. Assistance for children with disabilities also may be provided from the Respite Care and Abandoned Infants Assistance Act and from Child Welfare Services.

Housing

Medicaid. The Social Security Amendments of 1971 authorized Medicaid to pay for 24-hour care provided by licensed intermediate care facilities for the mentally retarded. Reimbursements for ICF/MR services have become the largest federally financed program for persons with mental or physical handicaps. In FY 1988, $3.38 billion in federal matching funds was allocated to states for ICFs/MR. Of that amount, 84 percent went to large facilities of 16 or more people.[35]

Foster Care and Adoption Assistance (P.L. 96-272). Foster home placement is one residential option for children who have handicaps. Foster Care and Adoption Assistance (sometimes referred to as Title IV-E based on its authorizing legislation) is a 100 percent federally funded program that makes monthly payments to families who adopt or provide foster care for children with special needs. Each state receives an allotment based on the number of children receiving Aid to Families with Dependent Children. The children automatically are eligible for Medicaid after adoption, regardless of the adoptive family's eligibility for Medicaid.

Department of Housing and Urban Development (HUD) Section 8 rent subsidies. Persons who earn up to 80 percent of the median income in their area are eligible for Section 8 rent subsidies. Some states have used a percentage of their Section 8 allocations for persons with developmental disabilities.

Section 202/8 Direct Loan Program for Elderly or Handicapped. This HUD program provides 100 percent direct federal loans for constructing, renovating, or acquiring housing to serve persons who are elderly or handicapped.[36]

Job Training and Placement

The (Vocational) Rehabilitation Act of 1973 (P.L. 93-112). This act, amended in 1986 as P.L. 99-506, authorizes over one billion dollars in federal support for services to help persons with mental or physical handicaps find jobs. Services include evaluation of job potential, counseling, referral, vocational training, transportation, interpreter services for persons who are deaf, reader services, job placement, and postemployment services. Participating states are required to provide these services to individuals, emphasizing persons who are most severely disabled, on a case-by-case basis, as determined by an individualized, written rehabilitation plan. State programs must conform to federal law and regulations to be eligible for federal matching funds. The 1986 amendments created a new funding stream devoted solely to supported employment programs.

Job Training Partnership Act (P.L. 97-300). The Job Training Partnership Act (JTPA) provides 100 percent federally funded job training for persons who are economically disadvantaged. They receive classroom training in vocational skills and basic skills, as well as on-the-job training or other assistance to help find employment. Provisions for supportive services include child care and transportation. The Department of Labor allocates funds by formula to state governors, who allocate funds to local market areas. Each area must establish a Private Industry Council to make decisions at the local level. In 1987-88, 46,350 adults with handicaps and 47,740 youth with handicaps were served under the JTPA.[37]

Income Support

Supplemental Security Income. This 100 percent federally funded program provides income assistance to low-income elderly, blind, and disabled individuals. Eligibility is limited to persons with disabilities who are not capable of "substantial gainful employment." Persons with some income who do not qualify for the whole benefit may receive a partial SSI payment. No restrictions are placed on how this money may be spent. In 1988, federal SSI payments provided roughly one million persons with disabilities[38] with two billion dollars in benefits.[39]

As of January 1, 1990, the benefit award is $386 per month for single persons and $579 for couples. States may elect to supplement this payment and target specific needs of individuals with disabilities, such as home care services or board and care. SSI automatically entitles the recipient to Medicaid in all but 13 states: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, Nebraska, New Hampshire, North Carolina, North Dakota, Ohio, Oklahoma, and Virginia.[40] These states have additional requirements that SSI recipients must meet to be eligible for Medicaid.

Persons who live in institutions funded by Medicaid cannot receive the full SSI benefits. They can, however, qualify for a reduced benefit of $30 a month to cover personal needs.

Adult Disabled Child Benefits. Adults who were disabled in childhood are eligible for Adult Disabled Child benefits based on the earnings record of a deceased, disabled, or retired parent. This federal program is funded by Social Security payroll deductions. The child allotment is an additional 50 percent above the parent's primary insurance amount, up to a family maximum of $1,200 per month. Adult children of a deceased worker receive 75 percent of their parent's benefit. In 1988, Adult Disabled Child benefits amounted to $1.8 billion.[41]

Social Security Disability Insurance. SSDI provides monthly benefits to workers who have paid into the Social Security system but are unable to continue working because of a physical or mental impairment. Average monthly payments are $508 for an individual and $919 for an individual with a family. The program is totally funded by the federal government from payroll deductions. Recipients are eligible for Medicare benefits after two years.

Persons with developmental disabilities who benefit from SSDI include minor children with an eligible parent who receives an additional monthly allotment for the child, and individuals who are eligible by virtue of their employment history. Because persons with developmental disabilities experience their disability early in life, few accumulate the quarters of Social Security coverage necessary to qualify for SSDI. However, given the trend of more competitive and supported employment for persons with developmental disabilities, professionals expect a growing number to earn at levels to make them eligible for SSDI. In addition, workers in nonprofit organizations are covered under SSDI. Potentially, this means that persons working in sheltered workshops or supported employment and earning as little as $400 per quarter could qualify for disability insurance and be entitled to cash benefits, Medicare coverage, and retirement income.[42]

Food stamps and Aid to Families with Dependent Children. Food stamps and AFDC provide eligible persons who have mental and physical handicaps with resources needed to survive in the community. Food stamps are provided with federal funding to supplement consumer cash income. Residents in group living situations who receive SSI benefits now are eligible for food stamps. AFDC authorizes federal matching payments to states for providing aid and services to families with children who meet the state's eligibility criteria.

Education

The Education for All Handicapped Children Act of 1975 (P.L. 94-142). This seminal act is intended to guarantee all children between the ages of five and 21 with handicaps a free and appropriate public education, including needed support services in the least restrictive environment. These services may include transportation, speech pathology, audiology, psychological services, physical and occupational therapy, recreation, counseling, diagnosis and evaluation, and early identification and assessment.

Federal funds are provided to states on a matching basis, with 75 percent of monies designated to local education agencies for educational services and 25 percent provided to state education agencies. Although the law provides for federal assistance to meet up to 40 percent of the excess costs of special education, in reality, federal assistance is much less. In 1986, federal expenditures for special education were $1.16 billion--substantially less than the estimated 12 percent of total education budgets that local school districts spend to educate students with handicaps.[43]

Early Intervention Program for Infants and Toddlers (Title I of P.L. 99-457). The first piece of federal legislation to recognize families as the primary caregivers for children with handicaps, this federally funded program is a breakthrough in federal disability policy. The far-reaching legislation provides funding for states to create a statewide, comprehensive, coordinated, multidisciplinary, inter-agency program of early intervention services for infants and toddlers with handicaps and their families by October 1, 1991. The final federal regulations issued by the Department of Education on June 22, 1989, emphasize family-centered services rather than child-centered and agency-centered services and contain a strong mandate for community integration. The regulations state that, where appropriate, early intervention services must be provided in the types of settings in which infants and toddlers without handicaps would participate. The program covers infants and toddlers from birth through age two if they are diagnosed as disabled or are determined to be at risk.

Federal Pre-School Program (Title II of P.L. 99-457). This act extends the rights and protections of the Education for All Handicapped Children Act to children with handicaps ages three to five by school year 1991-92. Just as the landmark Education for All Handicapped Children Act had a profound effect on persons ages five through 21, this recent act is expected to have a similarly significant impact on infants and toddlers.

Head Start. Project Head Start provides comprehensive developmental services to low-income pre-school children. At least 10 percent of the enrollment must be children with handicaps.

QUESTION FIVE: WHAT STATE AND LOCAL SOURCES FUND SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES?

State Support

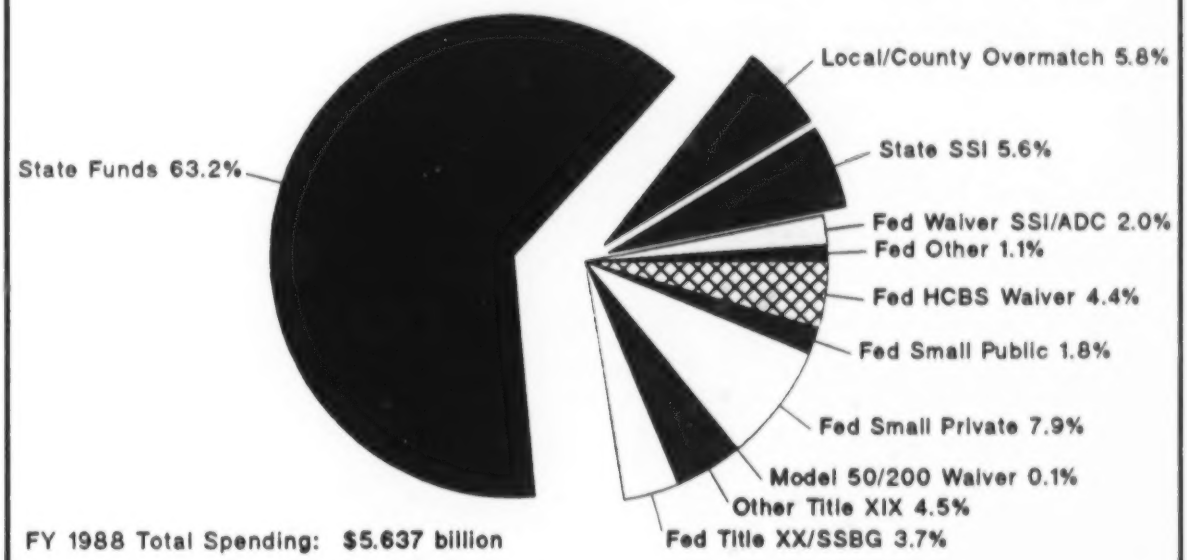
States are the centerpiece for providing and financing community services for persons with developmental disabilities. In addition to matching funds for many federal programs, states also provide 74.6 percent of the money for community services from state and local funds, amounting to $4.2 billion in 1988[44] (see Figure 1). The development of community services largely has been fueled by state initiatives. States also collectively spend slightly over one-half of their operating budgets on services to the more than 88,000 persons with developmental disabilities who still reside in state-operated residential facilities.[45] Further, states influence mental health financing by passing laws that regulate standards for public and private providers and third-party insurers.

Local Support

Many local governments provide matching funds to support services for persons with disabilities. Matching funds act as an incentive for local governments to raise local dollars and to participate in planning a cost-effective system of services for persons with developmental disabilities. In 1988, approximately 7.5 percent of the funding for community services was provided by local governments.[46] Funding for local/county services comprised more than 20 percent of total funding for community services in six states: Iowa, Kansas, Minnesota, Missouri, Ohio, and Virginia. Local or county funding was also a significant component of community resource spending in Arkansas, Illinois, Indiana, Michigan, Mississippi, Nebraska, Pennsylvania, Texas, and Wisconsin.[47]

Figure 1.

Community Services Revenue for Persons with Developmental Disabilities



FY 1988 Total Spending: $5.637 billion

Source: Braddock et al., *The State of the States in Developmental Disabilities* (Baltimore: Brookes Publishing Company, 1989), p. 510.

Note: See the Glossary and Acronyms for definitions.

QUESTION SIX: WHAT PUBLIC/PRIVATE PARTNERSHIP OPTIONS COULD BE USED TO SUPPORT HEALTH AND HOME SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES?

State government and individual families or private insurance companies can join in partnerships to provide health and home care to persons with developmental disabilities. The following strategies, most of which have been tried, are too new to evaluate but may hold promise for innovative ways to serve persons with developmental disabilities.

Self-Sufficiency Trust (SST). This innovative idea in estate planning originated in Illinois with the National Foundation for the Handicapped. Illinois was the first state to establish an SST, which allows parents with a family member who has a disability to contribute money to a Private Trust Fund where the money is pooled with that of other participating families. Returns on investments are credited proportionately to each family. Interest earned from this pooled trust is transferred to the counterpart State Trust Fund, which pays for supplemental goods or services via the existing service network. A life-care plan developed for each participant embodies the wishes of the parents and defines the intent and nature of supplemental services that will be provided to the beneficiary. Because monies technically become State Trust Fund monies, they are not viewed as earned or unearned income to the disabled beneficiary. Eligibility for government programs such as Supplemental Security Income and Medicaid is not affected.

A second fund, the Charitable Fund, is a repository that accepts residual and donated assets earmarked for all low-income and indigent persons with disabilities who are unable to participate in the Private Trust Fund. Upon the death of a beneficiary of the Private Trust Fund, 50 percent of the residual principal is donated to the Charitable Fund. Donations and bequests may be accepted from foundations, corporations, and private sources to generate income and expand services.

Self-Sufficiency Trusts exist in Illinois, Kansas, Maine, Montana, and Oregon. A number of other states are considering proposals to create these trusts, including Alaska, Florida, Georgia, Hawaii, Massachusetts, Michigan, New York, Ohio, and Virginia.[48] Supporters advocate a nationwide network of Self-Sufficiency Trusts allowing transferability among states.

Mandated employer-based coverage. Under this option, all employers with a specified number of employees are required to provide a minimum package of health benefits to persons working at least half-time. Federal legislation on this type of coverage, sponsored by Senator Edward Kennedy and Representative Henry Waxman, is currently pending.

Massachusetts is the first state to enact legislation designed to guarantee health insurance to all of its uninsured residents. By 1992, businesses with more than five employees will be required to pay a surcharge on each full-time employee's wages into a health insurance trust fund. Employers who provide health insurance can deduct those costs from the surcharge.[49] Individuals with disabilities can obtain primary and supplementary health insurance through CommonHealth, a program administered by the new Department of Medical Security. Under CommonHealth, children with a disability who have been denied Medicaid or Supplemental Security Income because of their parents' income and assets can purchase health coverage not provided by the family's private insurance.[50]

State high-risk pools. Because many high-risk individuals, such as persons with heart disease, cancer, and diabetes, have trouble obtaining private insurance, some states have enacted laws to create comprehensive health insurance associations, known informally as risk pools. These associations offer health insurance coverage to people who have been rejected by insurance companies and people who are not eligible for Medicaid, but who might exhaust their savings and become medically indigent as a result of an extended illness. Under the laws, all insurers doing business in the state are required to join the association, which offers individual, comprehensive health insurance to people who are

considered uninsurable. Some advocates propose that high-risk pools may be a viable option for insuring children with special health care needs.

At present, at least 15 states have created risk pools, including Connecticut, Florida, Illinois, Indiana, Iowa, Maine, Minnesota, Montana, Nebraska, New Mexico, North Dakota, Oregon, Tennessee, Washington, and Wisconsin.[51]

State subsidies for private health insurance. Low- and moderate-income families can purchase a private health insurance policy through the use of state vouchers in this model. Children with chronic illness may not benefit from this model because of a low lifetime maximum coverage or because the policy does not cover needed services. Moreover, even with a voucher, the private policy may prove to be too expensive. To counteract this, the state may select an insurer to offer a state-qualified benefits package to all persons eligible for the subsidy. A group plan would allow the risk to be spread across the populations.

Washington passed legislation in 1987 to establish a trust account to subsidize coverage for uninsured persons under age 65 whose gross family income is less than 200 percent of the federal poverty level. Enrollees pay premiums on a sliding scale and obtain services through a participating managed health care system. The legislature appropriated $27 million for a two-year period to subsidize the premium costs. Enrollment is expected to reach 30,000 people.

State-financed catastrophic health insurance. In a few states, the state functions as the payer of last resort for persons who have incurred substantial unpaid medical bills. The program serves the uninsured as well as the underinsured who have exhausted their benefits. Persons become eligible for assistance when out-of-pocket expenses exceed a certain dollar amount or percentage of the family's income. Alaska, Maine, Minnesota, New Hampshire, New Jersey, New York, and Rhode Island have or had catastrophic health programs in operation. Most of these programs have experienced high costs and utilization. Alaska, Maine, Minnesota, and Rhode Island have tightened eligibility requirements or eliminated funding for their programs.[52]

State-mandated catastrophic health insurance. Under this proposal, all state insurance companies would be required to offer catastrophic health insurance coverage, with subscriber premiums financing the program. Carriers would participate in an association or pool, which shares in the gains and losses on a proportionate basis. Families who are too poor to pay for any private insurance premiums would not be covered. However, states could choose to grant their Medicaid programs the authority to purchase catastrophic health insurance for Medicaid-eligible persons. The catastrophic health insurance would become applicable after a family or individual has expended a certain amount of out-of-pocket money--$5,000 per individual or $7,500 per family under the National Association of Insurance Commissioners' proposed model act. At present, no states have enacted this model.[53]

Although the approaches listed in this section may answer the health care needs of persons with developmental disabilities, these public/private partnership options do not address the important issue of long-term care services.

QUESTION SEVEN: HOW ARE STATES COMPLYING WITH NURSING HOME REFORMS?

The Omnibus Budget Reconciliation Act of 1987 requires states to eliminate inappropriate nursing home placement of persons with mental illness, mental retardation, cerebral palsy, epilepsy, autism, and other developmental disabilities. The law requires states to screen all existing nursing home residents by April 1, 1990. Federal reimbursement will cover 75 percent of the cost of screening. For nursing home residents who are mentally retarded or mentally ill and need active treatment, but not 24-hour care, the state must provide housing and treatment. Individuals who have lived in a nursing home for 30 or more continuous months prior to January 1, 1989, may elect to stay in the nursing home. States will be responsible for providing active treatment to those who choose to stay. Most states report that over one-half of all nursing facility residents with mental illness or a developmental disability have resided in such a facility for 30 months or more. Many are expected to remain in their current location,[54] although this does not have to be the case because OBRA authorized states to request special Medicaid nursing home deinstitutionalization waivers using the average daily ICF/MR cost to fund an array of home and community services.

The deadline for finding alternative placements for nursing home residents eligible for transfer is April 1, 1990. States that submitted an Alternative Disposition Plan were allowed to extend the deadline to 1994.[55] All but five states (Arizona, Alaska, Kansas, New York, and Wisconsin) and the District of Columbia have asked for an extension.

Most mental health and developmental disabilities officials applaud the reform's goal of properly serving people. However, the initial time line and the complex and constantly changing requirements coming from Washington, D.C., have strained state planning efforts.

The reform effectively shifts a massive responsibility to the states, which must find the funds to support housing and services for large numbers of new consumers, including services to persons who no longer have the option of going to a nursing home. Although many people believe that elderly persons with disabilities will be better served in ICFs/MR than in nursing homes, professionals have expressed concerns that some states simply will transfer persons from nursing homes to ICFs/MR, where federal reimbursement is available, thus slowing the gains of the past 20 years of moving persons from institutions to the community.

The number of people in nursing homes who will have to be transferred varies widely among states. Some states are experiencing a fairly smooth implementation of the new requirements and do not anticipate large expenditures, while other states foresee spending a lot of money to develop alternative placements.

Following are some states' experiences in complying with nursing home reforms:

Georgia. State officials estimate that a total of 6,210 persons with mental retardation or mental illness reside in nursing homes. Mental health officials have put together a package for the 1991 General Assembly that would place individuals requiring active treatment in structured treatment residences at a cost of $75 a day. An additional package of services such as day treatment and intensive behavioral shaping would cost an additional $15-20 a day. For nursing home residents who do not require active treatment, officials have proposed a $200 per month supplement to regular personal care home rates. Georgia expects to comply with the law by 1994.[56]

Illinois. Approximately 3,000 persons with developmental disabilities and 9,000 persons with mental illness reside in nursing homes in Illinois. State officials project that 600 persons with developmental disabilities will choose to stay in nursing homes. To accommodate the 2,400 nursing home residents with developmental disabilities who must move, Illinois plans to expand its Community Integrated

Living Arrangements, which include group homes of up to eight people, supported apartments, support for family homes, and other community placements. State planning efforts focus on consumer choice. The 1990 state budget contains $25 million to develop placements for persons with mental illness and developmental disabilities.[57]

Indiana. A 1985 Indiana public law mandated that all nursing home residents with mental disabilities be screened, and those inappropriately placed be transferred, giving the state a head start on OBRA-87 reforms. State estimates put the number of persons with developmental disabilities in nursing homes at 2,500. Officials project that approximately 700 people who need active treatment will elect to remain because of the 30-month option. An estimated 475 people are too elderly or frail to benefit from active treatment. Approximately 625 people will require active treatment, but not nursing home services.[58]

The state anticipates that most elderly clients who have to be moved will go to group homes. Some homes will require extra staffing. In determining placements, the state will make an effort to move elderly clients to the group home closest to their family members. Group home placements are funded by federal ICF/MR matching funds. The Department of Mental Health will require additional funds to expand services to comply with an Indiana law that requires anyone in a community residential facility to receive day services outside the facility for six hours a day, five days a week.[59]

South Dakota. In South Dakota, 142 persons with developmental disabilities reside in nursing homes. Since 90 percent of the people have been in nursing facilities for more than 30 months and will have the option of remaining, state officials anticipate relatively few will need to be transferred. The state has a Medicaid home- and community-based waiver that provides funds for all programs for active treatment, except for room and board. Officials expect Supplemental Security Income to cover the room and board of those who are transferred to other settings. The state has until 1993 to complete the placements.[60]

Texas. In February 1989, the Texas Health Care Association brought suit against the federal Health Care Financing Administration, the federal Department of Health and Human Services, the Texas Department of Mental Health and Mental Retardation, and the Texas Department of Health. The U.S. District Court for the Western District of Texas granted a temporary injunction, stating that nursing home residents were harmed by the failure of the cited parties to come forth with rules to comply with the OBRA-87 regulations. Persons with mental or physical handicaps may stay in nursing homes as long as the injunction is in place. State officials are still interpreting the injunction and it is unclear when it will be lifted.

In the meantime, Texas officials are proceeding with the identification of those who need alternative placement. Approximately 3,500 persons with developmental disabilities are in nursing homes at present. One-half have been there for 30 months or more. The Alternative Disposition Plan that Texas presented to the federal government calls for the Mental Retardation Authority to provide active treatment to people who choose to stay in nursing homes. The estimated cost is $10.1 million for 1990 and $22.4 million for 1991. Most people who are inappropriately placed in nursing homes will be moved to ICF/MR beds. The alternative placements are slated to begin April 1, 1990, but nothing will be done until the injunction is lifted.[61]

Wisconsin. In 1985-86, the federal Health Care Financing Administration negotiated an agreement with Wisconsin to have all nursing home residents with developmental disabilities moved to appropriate settings by July 1, 1990. The state was well along in the process by the time OBRA-87 requirements were adopted. State officials estimate that 3,000 persons with developmental disabilities reside in nursing homes, with 2,500 slated to be moved and 500 to stay. The state is developing "distinct part" ICF/MR beds. These are geographically separate units in nursing homes, which will be reimbursed through Medicaid ICF/MR funds. Approximately 500-700 people will move to supported community residences of one to three people or group homes of four to six beds.[62]

QUESTION EIGHT: WHAT ARE STATES DOING TO PROVIDE CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES?

Innovative state efforts attest to the fact that quality services can help persons with disabilities live and work in the community. The programs discussed in this section include family support services, housing, integrated education, supported employment, and transition services. Program contacts are listed in the Notes.

Family Support Services

The vast majority of adults and children with developmental disabilities benefit from living with families. Yet, until recently, service systems often made it easier for families to send their children with handicaps away to receive services. Many states are moving to correct this by establishing support services to help parents and their children with handicaps stay together.

At present, approximately 29 states provide services and resources to families who care for a family member with a disability in the home. Ten states have a cash subsidy program, 10 fund family support services, and nine offer families a combination of financial assistance and support services.[63] Table 2 shows state family support spending as a percentage of total spending for individuals with developmental disabilities. These state programs help deter unnecessary and expensive out-of-home placements, return persons living in institutions to a family setting, and make families' lives easier and better.

The family support programs in Maryland, Michigan, New Hampshire, and Wisconsin are distinguished by placing much of the control of services in the hands of families and by offering flexibility to respond to the unique needs of each family's situation.

Maryland. In 1986, the Maryland General Assembly revised its law concerning developmental disabilities to mandate the provision of family support services. Maryland's family support program aims to support families on the basis of the entire family's needs, rather than just the needs of the child with a handicap. In 1989, 565 clients were served through the family support program at an average cost of $1,200 per family. Seven providers in four regions offer family support services. The types and level of support vary, but may include the following:

- *Financial support*. Financial support may come in the form of ongoing assistance or a one-time cash payment of up to $40,000 (the yearly cost of a full residential program) for specialized equipment or adaptation to the home.

- *Individual family counseling*. In keeping with the program's family-centered approach, support is based on social and personal needs as well as financial and medical needs.

- *In-home care for children with medical needs*. The Coordinating Center for Home and Community Care (CCHCC) provides service coordination for children, many of whom have spent much of their lives in nursing homes or hospitals. Prior to a child's discharge from the hospital, CCHCC arranges a meeting with the parents, the physician, the home-care providers, and a representative of the payer--either a private insurance agency or Medicaid, through the Home- and Community-Based Services Program waiver. Before the child returns home, hospital staff train parents in all aspects of care. The parents then hire and train their own nurses, with assistance from CCHCC. A clinical coordinator visits families once a week for the first month, once every other week for the next month, and once a month thereafter.

Table 2.

Family Support Spending as a Percentage of Total MR/DD Spending: FY 1988

	Total Family Support		Total 1988 MR/DD Expenditures	% Family Support of Total MR/DD Expenditures
	Expenditures	Clients		
Alabama	$ 325,000	n/a	$ 94,695,432	0.34
Alaska	718,900	436	20,266,200	3.55
Arizona	3,975,900	1,781	77,738,400	5.12
Arkansas	206,000	40	71,371,311	0.29
California	30,511,839	32,913	1,137,788,802	2.68
Colorado	289,894	n/a	111,732,777	0.26
Connecticut	1,903,409	1,492	383,182,056	0.50
Delaware	80,352	266	29,322,358	0.27
D.C.	493,082	430	66,238,000	0.74
Florida	11,285,234	n/a	302,578,944	3.73
Georgia	611,562	1,056	218,652,454	0.28
Hawaii	115,000	400	25,567,528	0.45
Idaho	113,500	372	34,573,845	0.33
Illinois	12,315,500	12,050	476,636,556	2.58
Indiana	370,542	1,000	176,350,195	0.21
Iowa	0	0	127,860,155	0.00
Kansas	0	0	96,418,039	0.00
Kentucky	2,732,957	n/a	72,687,173	3.76
Louisiana	45,743	169	172,470,424	0.03
Maine	197,306	500	55,107,449	0.36
Maryland	4,050,136	2,008	214,695,908	1.89
Massachusetts	18,900,000	n/a	605,835,795	3.12
Michigan	14,679,251	n/a	455,760,259	3.22
Minnesota	2,680,700	n/a	304,618,737	0.88
Mississippi	0	0	70,359,690	0.00
Missouri	536,655	500	177,526,268	0.30
Montana	2,844,400	1,755	33,609,780	8.46
Nebraska	0	0	65,839,307	0.00
Nevada	162,200	70	16,793,773	0.97
New Hampshire	936,174	1,285	63,139,614	1.48
New Jersey	8,793,000	n/a	476,633,018	1.84
New Mexico	187,770	224	37,803,922	0.50
New York	16,536,000	20,000	1,806,816,303	0.92
North Carolina	1,072,900	1,395	245,415,000	0.44
North Dakota	777,200	n/a	65,034,408	1.20
Ohio	3,562,462	n/a	480,658,581	0.74
Oklahoma	0	0	101,988,275	0.00
Oregon	0	0	115,149,531	0.00
Pennsylvania	10,086,219	15,639	683,270,801	1.48
Rhode Island	1,700,000	175	82,192,060	2.07
South Carolina	1,422,100	241	145,674,304	0.98
South Dakota	0	0	35,680,933	0.00
Tennessee	104,860	187	118,996,451	0.09
Texas	9,642,656	3,649	507,360,399	1.90
Utah	447,100	n/a	63,892,876	0.70
Vermont	588,500	420	30,030,440	1.96
Virginia	0	0	184,297,100	0.00
Washington	2,466,094	900	176,346,420	1.40
West Virginia	114,850	n/a	36,691,521	0.31
Wisconsin	2,524,160	3,428	221,824,183	1.14
Wyoming	0	0	23,626,200	0.00
United States	171,107,307	104,781	11,398,799,956	1.56

n/a – Information not available
Note: This table includes funds that achieved budgeted status in the states' principal MR/DD state agencies, either in the form of a line item in the budget or in the agency's internal accounting and planning systems.
Source: The University of Illinois at Chicago, University Affiliated Program in Developmental Disabilities, 1989.

- *Family advocacy*. One of the objectives of the family support program in Maryland is to help families help themselves. Families are taught how to identify and obtain access to needed resources and support. Agencies work with families to help them develop competency as advocates for their child.

- *Other services*. Depending on the family's needs and the availability of services, families also may receive day care, respite care, personal care, and transportation.[64]

Agencies in Maryland are making an effort to obtain available federal funds and pool multiple sources of funding to meet the needs of families, including the following:

- *Model 50 waiver*. In Maryland, this waiver provided in-home supports to 50 children with complex medical needs in 1987-88.

- *Medicaid Technology-Assisted waiver*. This waiver provides funds for children with complex medical needs who require the assistance of technology, such as ventilators.

- *SPRANS grant*. The Special Projects of Regional and National Significance grants, available through the federal Maternal and Child Health block grant, fund agencies that provide case management and service coordination to children with complex medical needs.

- *Developmental Disabilities Administration (DDA)*. This state agency provides funds for family support services.

- *Developmental Disabilities Council*. This state council has used some of its funds to initiate and expand family support services.

- *Private foundations and organizations*. Grants or support to help fund family support services also come from the Hearst Foundation, United Cerebral Palsy Associations, Inc., and the Society for Underprivileged and Handicapped Children, among others.[65]

Michigan. Michigan, a state of nine million people, is a recognized leader in transferring persons with handicaps from institutions and serving them in the community. From 1975-1989, institutional populations have declined from approximately 6,500 to 1,200, an 81 percent decrease. The institutional population continues to decrease by an average of 300 people annually. In the 1980s, Michigan closed five state institutions. The state has a goal of returning all children from state institutions to the community. In 1989, fewer than 50 children remained in state centers.[66]

The institutional system has been replaced by residential community programs delivering services to more than 10,000 persons with developmental disabilities.[67] An array of care is available, including family support services, subsidy programs, adoption programs for abandoned children with handicaps, specialized foster care intervention, group homes, and semi-independent living arrangements. Support services that help families care for children with disabilities in the home include cash subsidies and respite care.

The Family Support Subsidy Act was passed by the Michigan Legislature in 1983, with strong support from parent and advocacy groups. Before the act's passage, the family support program was piloted in Macomb County. Proponents of the legislation emphasized the need for children with disabilities to remain with their families and contended that the act would result in a cost savings to the state by preventing out-of-home placements and encouraging families to take their children from institutions and other alternative placements.

In Michigan, the state pays direct cash subsidies of approximately $225 per month to families of children with severe disabilities who otherwise would require expensive institutional care. The subsidy

helps defray the costs of maintaining the child in the home, such as specialized equipment, respite care, and home renovation. To qualify for the subsidy, a family must earn a taxable income of less than $60,000 and have a child under age 18 with a severe disability. After that age, the person becomes eligible for Supplemental Security Income.[68]

About 3,200 families participate in the Family Support Subsidy Act program at an annual cost of approximately $8.6 million.[69] Officials believe the program is cost-effective. The average cost of the subsidy program per child per day is $7.50. Since institutional care costs average $200 a day, if only one child returns from an institution or is prevented from entering, the savings is more than $70,000 annually.

An example of the flexible array of respite care choices offered to families is the program at Community Services for the Developmentally Disabled (CSDD), operated by the Community Mental Health Board serving the three-county area around Lansing, Michigan. In 1989, the program provided eligible families with $210 worth of respite services per quarter, including:

- *Foster home respite care*. Care is provided in licensed foster homes by providers trained individually to work with the child. After training, the family makes arrangements with the provider directly. The service costs $25 per full day and $12.50 per half day.

- *Home-based respite care*. Part-time CSDD employees are trained to deal with children who require medical procedures, such as gastronomy tube feedings. The trained employees come to the home to babysit. The family pays $4.75 an hour.

- *Family/friend respite care*. Family friends or relatives are paid up to $3 per hour to provide respite care.

- *Drop-in day care center*. Eight spaces are provided on a first-come, first-served basis on Saturdays from 10 a.m. to 9 p.m. at a cost of $3 per hour.

In 1988-89, 263 families received respite care under this system, which allows families to select the type of respite care that best fits their needs.[70]

New Hampshire. The New Hampshire General Court appropriated close to $3 million for fiscal years 1990 and 1991 to establish a family support network for families caring for children or adult family members with disabilities at home. The innovative aspect of this network is the extraordinary amount of power parents have been given to determine what services will be delivered, and how. In each of New Hampshire's areas, a family support council consisting of persons who have family members with disabilities will negotiate for support services with area service agencies and providers. The parents, who are in the best position to know what services are required, will be responsible for selecting area providers, based on plans they submit to the council.[71]

Wisconsin. Wisconsin is widely recognized as having one of the most innovative family support programs in the country. It is noted for its flexibility and consumer orientation. The state's family support program began in 1984 as a demonstration project of Wisconsin's Council on Developmental Disabilities and was established by law the following year by the legislature. Started in 11 counties, the program will extend to all 72 counties by 1991. The program pays for any goods and services needed to support children with handicaps in the home. Instead of making the family fit the services, services are tailored to fit the family.

Families of children with severe disabilities are eligible for up to $3,000 worth of services annually, regardless of their income. Families choose from a menu of available services. These include architectural modifications, child care, counseling, uncovered medical and dental expenses, specialized diagnosis and evaluation, nutrition and clothing, specialized equipment and supplies, homemaker

services, in-home nursing, home training, recreation, respite care, transportation, specialized utility costs, and vehicle modification. The average cost of the family support program is $1,800 a year.

Each family receives a needs assessment and individual service plan. The plan details what services the family receives through the program and what services will be obtained elsewhere. Staff members are encouraged to make creative use of community resources, such as recreation programs, medical and dental services, public transportation, and other service providers. The family is active during the service planning process and must approve the service plan.

Wisconsin's Family Support Program is administered by the counties, which either provide services directly or contract with local agencies. State legislation requires that 90 percent of funds allocated to counties for family support programs be spent directly for services. The rest is used for staff and other administrative costs. Wisconsin's Family Support Program has served as a model for programs started in Connecticut, Georgia, Massachusetts, New Hampshire, Texas, and Washington.[72]

Housing

Housing is a critical component of community services. Persons with mental retardation and developmental disabilities need flexible support services, ranging from assistance with personal hygiene, cooking, and budgeting, to more extensive supervision. The Macomb-Oakland Regional Center in Detroit, Michigan, the Region V Mental Retardation Services in Lincoln, Nebraska, and the housing programs in Wisconsin are notable for the range of small-scale, family-like residential choices available to clients.

Michigan. Located in the two suburban counties north of Detroit, the Macomb-Oakland Regional Center is widely recognized as a national leader in innovative services and has developed more community living arrangements for people with severe disabilities than any other service system in the country. More than 60 percent of the state agency's 1,300 clients are severely or profoundly mentally retarded. Macomb-Oakland employs 237 professional staff and centrally provides all professional services. Residential and vocational services are contracted out to private, nonprofit agencies. Macomb-Oakland's community services are organized into the following five divisions:

- *Development*. Eleven full-time staff specialize in developing specific kinds of community living arrangements. Five members focus on foster families and six work exclusively on group homes.

- *Placement*. A team of professionals reviews every person's placement to ensure an appropriate match. Placement staff also are in charge of coordinating family support services.

- *Support services*. Professional services are centrally provided at Macomb-Oakland. Professionals include psychologists; physical, occupational, and speech therapists; nurses; dieticians; physicians; and a sex education specialist. The psychologists specialize in behavior management and provide training and consultation to contract agencies. For the most difficult clients, Macomb-Oakland has a budget of $2 million to provide one-to-one staffing.

- *Case management*. Case management is separate from service delivery to help maintain quality. Case managers are expected to play an aggressive monitoring role, making unannounced visits. They must also work a certain number of nights and weekends. The average caseload is 24 clients.

- *Vocational services*. Macomb-Oakland contracts with 13 private agencies for vocational services and day programs for approximately 943 people. A majority of placements are in traditional sheltered workshops and prevocational training centers, although the center is developing other options.

At Macomb-Oakland, institutional placement is avoided. The program has made a strong commitment to keep handicapped children with their natural families. If this is not possible, adoption or foster home placement is pursued. Some children are placed in "open adoption," a nonlegal arrangement whereby a family gives a child up for adoption, but the adoptive family agrees to cooperate with the birth parents' visits and continuing involvement. For clients who do not live with their natural or adopted parents, five residential options are available:

- *Foster homes/community training homes*. Approximately 15 percent of Macomb-Oakland's clients, all under age 18, live in foster homes. In 1989, foster families received $28 per person per day ($10,220 per year). Recruiting foster parents is a priority at Macomb-Oakland, which employs full-time specialists to recruit and screen foster families. Aggressive recruiting techniques are used to identify potential foster families, including advertisements, public service announcements, newspaper articles, newsletters, flyers, posters, and referrals from other people. The staff works hard to match the child to the family. Some families are better with children who have behavior problems and others are better with medically fragile children.

- *Adult foster care*. These foster homes for up to four people have budgets to hire staff and supplement family members. Families are paid $35 to $49 dollars per person per day ($12,775 to $17,885 a year).

- *Group homes*. Limited to no more than six people, group homes began to receive Medicaid reimbursement through 2176 waivers in 1988.

- *Alternative Intermediate Service Homes*. These homes for up to six people are certified and reimbursed by Medicaid's Intermediate Care Facilities for the Mentally Retarded Program.

- *Supported Independence Program*. One or two persons with mild disabilities live in an apartment, house, or duplex and receive staff support as needed. Support services may include rent subsidies; transportation; homemaker services; counseling; home health care aids; and social, recreational, and medical support. In 1989, 74 people were living in these semi-independent residences.[73]

Recently, Macomb-Oakland programs have been moving almost entirely to support services in the natural home.

Nebraska. In 1973, the Nebraska Legislature established six mental retardation regions in the state to ensure area program support and coordination. Region V serves the 16-county area around Lincoln, Nebraska. The region is subdivided into 10 area programs with seven area directors. The Region V office sets policy, establishes general procedures, implements monitoring and evaluation systems, and approves area agency budgets. However, area directors have great flexibility in designing services to meet local circumstances.

Region V is committed to the idea that all persons with mental retardation and developmental disabilities belong in the community, regardless of the severity of the disability. Residential services are provided to 400 people, with an emphasis on smaller service settings. In the past 18 months, no person with mental retardation has been admitted to an institution.

Officials believe that two or three individuals living together with a staff person provides a richer learning environment than large group settings. Only 10 five-person group homes remain. The rest of the residential consumers live in a variety of living arrangements, including:

- *Foster care and extended family homes*. Region V staff recruit, screen, and train families or individuals to care for one to three people with mental retardation in their homes. In 1988-89, 56 children and 33 adults were served. Viewed as the model of choice because of the strong bonds established, foster families are paid $337 a month per person for room and board. Extended families, which are foster families that offer additional training and services, are paid an additional $200 to $500 per month. Some extended families also receive 10 days a year for vacation and from 10 to 20 hours a month for in-home assistance, depending on the needs of the child.

- *Mini-group homes*. These homes for three or four people have a staff person present at all times the consumers are there. In 1988-89, seven children and 119 adults lived in these homes, which included rented houses, townhouses, and apartments.

- *Supervised apartments*. Approximately 60 people rent their own houses, apartments, or trailers and receive staff support to help them cook, clean, budget, and care for themselves.

The Region V programs do not segregate people by disability. Persons with mild retardation are served with people who have severe mental retardation. Staff members must deal with a range of needs and abilities. This reduces staff burn-out and prevents people with similar disabilities from learning the wrong things from one another.

Region V has achieved what is widely viewed as one of the most innovative systems in the country with relatively few financial resources. The total cost of residential and other services ranges from $22,000 to $30,000 per person per year. Many of these people have severe disabilities. Medicaid ICF/MR funds are not used to support community services.[74]

Wisconsin. Services for persons with developmental disabilities are administered by 51 quasi-independent community service boards in Wisconsin. Certain counties and agencies are developing some of the most innovative and responsive community living arrangements in the country. With the support of Wisconsin's Community Integration Program, the state's Medicaid waiver program funds services for persons coming out of institutions. These include:

- *Small group homes*. These agency-operated apartments or houses for two to four persons resemble shared living more than group homes. Support services are flexible and tailored to the needs of the individual. Persons with mild disabilities may need someone only to drop by occasionally and check in. Persons with severe disabilities may need full-time support.

- *Options in Community Living*. This private, nonprofit agency based in Dane County provides support services to clients with disabilities who rent their own houses or apartments. In 1987, Options in Community Living supported approximately 100 people living in the community. Clients hire their own staff, referred to as attendants. The agency acts as a broker, recruiting attendants and training and teaching clients how to supervise their own attendants. In some cases, Options in Community Living uses foster care funding and licensing to arrange for "paid roommates" who provide companionship and support in the clients' homes. At first, the program focused on persons with mild mental disabilities. But recently, with special funding from Wisconsin's Community Integration Program, this program has begun to serve people coming out of institutions who have more challenging needs.

- *Support workers*. Columbia County contracts with a private agency to hire support workers, or "friendly visitors" to help persons with developmental disabilities up to 20 hours per week in their homes. Depending on the needs of the individual, support workers might help a person go to church, shop for groceries, or attend recreational activities in the community.

- *Start-up funds for new households*. Columbia County has reserved funds to help people with the security deposits and start-up expenses of setting up a new home. The county director buys materials on sale and stockpiles bicycles, dishes, brooms, and other household goods. Television sets can be rented and purchased over time.[75]

Integrated Education

Since the 1975 Education for All Handicapped Children Act promised all children with handicaps a free, appropriate education in the least restrictive environment, parents, educators, and advocates have pushed to have children with handicaps educated in the same classrooms as their nonhandicapped peers. However, practice has lagged behind theory. While programs vary greatly from state to state, and among districts within states, school systems in Vermont, in Madison, Wisconsin, and in Johnson City, New York, are showing that children with handicaps can be integrated successfully into regular classrooms.

Vermont. Approximately 85 percent of children with developmental disabilities are educated in regular classrooms in Vermont. The other 15 percent are children with severe emotional disturbance, who are educated in regional schools, and older students with learning impairments, who participate in special vocational programs. To help integrate the children who still remain in segregated settings, the Center for Developmental Disabilities at the University of Vermont, working closely with the Department of Education, has developed a number of programs:

- *The "I" Team*. Teams of specialists help the students with the most severe handicaps across the state to be educated in regular schools. The state is divided into five regions. Each has a regional education specialist, a part-time paid support parent, and an occupational or physical therapist. In addition, a core team, based at the Center for Developmental Disabilities, covers the state as needed. Assistance may be requested by the regional specialist, the educator, or parents.

- *The Homecoming Model*. This collaborative, statewide approach relies on teams to develop the support services needed to transfer students from regional special education programs and place them in regular classrooms. A school board member, a parent, and regular and special educators comprise the team.

- *Project Wrap-Around*. This program provides intensive home- and school-based support services to families who have children at home who are at risk of being placed in an alternative residence. The program "wraps" services around the child, providing whatever is necessary to keep the child in the home and in an integrated educational setting. For example, a coordinator may provide from five to 30 hours a week of training to help parents care for their children. Other support includes respite services, support groups, marriage counseling, and substance abuse counseling--anything necessary to relieve the stress caused by caring for a child with a severe disability in the home. The school-based training includes child counseling.[76]

Wisconsin. The school district in Madison, Wisconsin, serves 22,000 children, including 2,100 children with handicaps. Madison closed all its special schools in 1977. Today, all children with handicaps

attend regular schools. The Madison school system has initiated pilot projects to explore variations on ways to integrate children with handicaps into regular classrooms. These include:

- *Full integration*. Children with mental retardation are educated in regular classrooms with their nonhandicapped peers. Special education teachers come to the classroom for certain subjects, such as math, and teach the students with handicaps jointly, or in a parallel way, with the regular teacher.

- *Partial integration*. Children with mild, moderate, or severe retardation have a permanent seat in classrooms with other children with handicaps, but leave during the day to attend classes with their nonhandicapped peers.

- *Resource model*. Children with handicaps have a seat in the regular classroom but go out for special classes with other students with handicaps.

- *Team teaching model*. At 10 elementary and middle school pilot sites, two teachers jointly teach in classrooms where approximately 10 children with learning disabilities are taught side by side with their nonhandicapped peers.

- *Community instruction model*. During the day, a teacher takes two to three children into the community to learn special skills, such as how to take the bus, buy personal items, buy lunch, or purchase other items at a store. The instruction takes place not in classrooms but at banks, drug stores, fast food restaurants, or bus stops.

- *Vocational instruction*. Young people with handicaps in the upper grades work from one to two hours a week at 150 work sites in the community, including hospitals, offices, and plumbing stores.

The curriculum for children with handicaps is divided into four domains: domestic, leisure, community, and vocational. Training at each level is focused on preparing the child for the next level. For example, in elementary school, children are prepared for middle school. In high school, young people are prepared to get jobs. Instruction in the natural environment is emphasized. The goal is to make children with mental or physical handicaps as independent as possible.

This curriculum has been achieved by team work. School officials believe that children with handicaps cannot be integrated until the staff is integrated. The special education staff and support staff work closely with school principals, teachers, and other educational staff. Each school building has a team that works with children who need help, including children with handicaps. A psychologist, a nurse, a social worker, and a speech and language therapist comprise the team.

The school district is moving in the direction of placing children with handicaps in their home schools, whether or not special education classrooms exist. The 12-year effort has been achieved with the attitude of "a little at a time."[77]

New York. Located on the New York-Pennsylvania border 90 miles south of Syracuse, Johnson City educates 2,700 school children in two elementary schools, one middle school, and a high school. Three years ago, the school district began an aggressive program to transfer all children with handicaps who were educated at a special school run by New York's Boards of Cooperative Educational Services to their neighborhood schools, where they would be educated alongside their nonhandicapped peers. Today, approximately 150 children with handicaps, or 90 percent, are attending regular schools. These include students with severe and moderate impairments. The remaining 10 percent are children whose parents preferred that they remain in special schools, and students who are deaf or hearing-impaired.

In the elementary and middle schools, special education students are taught in regular classrooms by teaching teams. Three regular teachers, one special education teacher, and two aides, one specializing in students with handicaps, teach groups of 90 to 95 students. The team plans how to integrate the special education program with the regular program.

In the high school, students with mild impairments go to regular classrooms and receive supplementary help from a special education teacher for one to two periods a day. Young people with severe impairments attend classes taught by special education teachers. The district is working to integrate more fully these students.

School officials feel that, in the long run, integrating children with special needs saves money. Although the district hired 13 special education teachers and lost some state aid because the integrated program could not easily identify what percentage of services were devoted to special education, the district no longer has to pay tuition to special schools for the 150 students. For the past 18 years, the Johnson City schools have been developing an educational model based on mastery learning, which stresses that all students can learn well, provided that favorable learning conditions are present. Philosophically, the school district supported excellence for all, not a few. The superintendent soon realized that sending children with severe disabilities outside the district to be educated resulted in an inconsistency in that philosophy. After extensive discussions, administrators and faculty representatives decided to return students with severe handicaps to their neighborhood schools. The teaching teams were already in place, which made integration easier.

Today, three years later, parents who initially were concerned that children with handicaps would require all the teachers' time have come to realize that their fears were unfounded, according to school officials. A vast majority of the teachers also support the education of children with handicaps in regular classrooms.[78]

Supported Employment

Individuals with serious handicaps previously were thought to require training at sheltered workshops or adult training centers before entering the work force. However, recent vocational training research questions the benefit of pretraining, particularly for persons with severe disabilities, who may spend years of preparation in sheltered workshops and adult training programs. Given the right support services and effective training, even persons with severe disabilities can become productive members of the work force. In doing so, such persons simultaneously reduce public welfare expenditures, pay taxes, and contribute money to the state economy.

Many states have made significant progress in converting their day programs and sheltered workshop slots to supported employment. These include Georgia, Maryland, Virginia, and Washington.

Georgia. In 1987, Georgia's Mental Retardation Services notified its 130 publicly operated and private nonprofit day programs to transfer as many people as possible to supported employment on a voluntary basis. Unlike day programs, where people with handicaps are grouped together to perform tasks under supervision, supported employment offers disabled people the chance to perform a job in a competitive work environment, often alongside people who do not have handicaps.

By 1989, 600 persons with mental retardation were participating in supported employment programs in Georgia, 9 percent of whom had severe or profound retardation. Day programs continue to serve 5,800 people. Persons with developmental disabilities other than retardation are served by Rehabilitative Services.

All day program vendors wanting to transfer people to supported employment submit to the state a plan with resource and staff requirements. The vendors are paid a fixed amount for each client who

meets the criteria for supported employment ($6,084 for FY 1990). In the past three years, one-half of the day programs have converted at least some of their slots to supported employment.

As of April 1989, 598 persons with disabilities were served in supported employment at an average gross of $350 a month, or $3.18 an hour. The average number of hours worked per month was 26. Of these clients, 61 percent were on the employer payroll, and 14 percent were receiving health insurance benefits. The program is funded by state mental retardation and developmental disability funds, which are derived largely from state general funds, with some contribution from the federal Social Services block grant (SSBG).

Georgia's experience with supported employment has been positive, according to state officials. Clients who earned the sheltered workshop average wage of 41 cents an hour several years ago are now making an average of $3.18 an hour. Last year, clients in supported employment contributed $2 million to the Georgia economy, an amount that will continue to grow as the program expands. This has made a dramatic difference in their lives, giving the clients more financial power, greater independence, and more self-esteem as they become productive members of the community.[79]

Maryland. In Maryland, the state Developmental Disabilities Administration publicly endorsed the idea that people with disabilities have the right to lead a normal life, including holding a job. The administration announced that 85 percent of all expansion money would go to supported employment. Working with day program operators, the administration determined that 65 percent of the clients could be served in supported employment and established that figure as a goal. The program began three years ago with a five-year grant from the federal Office of Special Education and Rehabilitative Services (OSERS).

The Baltimore-based Kennedy Institute, a private, nonprofit agency, was selected to serve as the broker to make sure program plans were carried out. The institute works with state government to revamp procedures, provides technical support to programs converting from day program slots to supported employment, and works to influence policy. Members of the institute also visited 88 Social Security Administration offices to explain supported employment to claims handlers so clients would not lose their benefits. Consumers may call a special telephone hotline with questions about benefits.

In 1989, three years into the program, the state has converted approximately 30 percent of its day program slots to supported employment, one of the best records in the country. The rate of conversion differs widely among regions, from a high of 50 percent in the southern part of the state around Washington, D.C., to a low of 20 percent in the western rural mountain region. Today, approximately 1,100 persons with disabilities have supported jobs with 268 employers, including Marriott Hotels, Pizza Hut, Radio Shack, J.C. Penney, Red Lobster, and Ramada Inn. Clients earn an average hourly wage of $3.68 and work an average of 29.7 hours per month. A 1988 evaluation found that more than one-half of the clients stayed at the job and earned increasingly higher wages.[80]

Virginia. Virginia assists approximately 1,000 persons with disabilities in supported employment. State preference for converting from sheltered workshops to supported jobs is communicated to the community service boards responsible for services, through start-up grants to convert programs, agency guidelines, and new funds directed at supported employment programs. Persons in supported employment work an average of 28 hours a month and earn an average of $3.69 an hour.

Virginia is working to get the clients to pick up a share of the costs of a job coach. This will be accomplished through federal work incentive initiatives such as Plan to Achieve Self Sufficiency (PASS) and Impairment-Related Work Expense (IRWE), which prevent persons with disabilities from losing their Supplemental Security Income when they get a job. These programs allow the consumer to use SSI funds to purchase his or her own services and pay for transportation, assisted technology, and a job coach.

Because clients and local Social Security counselors are not familiar with these programs, the state Department of Mental Health, Mental Retardation, and Substance Abuse Services will provide training to help individuals take advantage of the provisions to which they are entitled. State officials estimate that Virginia has used several million dollars from SSI on supported employment. As more individuals statewide learn how to use federal dollars to pay for job coaches and transportation, state money will be freed for use by persons with severe impairments.[81]

Washington. In the early 1980s, the Washington Division of Developmental Disabilities took a leadership role in encouraging counties to develop programs in integrated community settings. Guidelines directed counties to find integrated employment for persons with disabilities. As a result, when the state received a grant from the federal Office of Special Education and Rehabilitative Services for supported employment, the state was well on the way to converting from day programs to supported employment. Of the 3,440 people in all vocational programs at the end of 1988, 1,400 were in supported employment. Persons with handicaps work in a wire and print shop at Boeing, in the electronics industry, and for Weyerhaeuser, a timber company. The average monthly wage is $482 for individuals in regular jobs; $157 for members of mobile crews, where teams of workers are sent into the community to perform maintenance, groundskeeping, or similar tasks; and $206 for people working in enclaves, where small groups of persons with disabilities are trained and supervised together in the midst of an ordinary work environment.

One long-range goal of the Washington Supported Employment Initiative is to change the way union and business officials think about persons with disabilities so supported employment jobs can become embedded in the community. The initiative aims to look beyond janitorial and high-turnover jobs for persons with handicaps. To achieve this, members of the Supported Employment Initiative are working to educate larger companies in the business community about people with disabilities. Under a research grant, initiative members will try to determine if the perceived barriers to supported employment among union leaders are a myth.[82]

Transition Programs

Many young people with mental or physical handicaps are unable to find employment and other support services after graduating or exiting from high school. To help young people make the transition from school to jobs, some states are developing specific programs, called transition programs, to help graduates of special education classes get and keep jobs.

Massachusetts. A 1983 state law created a transitional program for young adults with severe disabilities who graduate from public schools. The local school systems refer students to the appropriate human service agency, such as the Departments of Mental Health, Mental Retardation, Social Services, Public Health, or the Commissions for the Deaf or Blind. If the student has multiple handicaps and the schools cannot determine which agency is appropriate, the referral is sent to the state Bureau of Transitional Planning. The designated transitional agency assembles a team to develop an Individual Transition Plan, which maps out the steps required to help the graduate achieve stable employment. (The young adult with a disability, the parent or guardian, and representatives from the human service agencies, the school, and an appropriate economic affairs agency comprise the team.) Completed no later than six months from the graduation date, the plan details which services will be provided by which agency, and for how long. The designated agency acts as case coordinator for the client in the transitional program. The transitional program receives approximately 1,000 referrals a year. In 1988-89, approximately 300 clients were served with state funds and 300 with federal funds.[83]

New Jersey. New Jersey launched a statewide initiative to help 500 public school graduates with developmental disabilities find competitive jobs in the private sector. Job coaches provide direct on-the-job training at the work site, working side by side with the disabled employee to help him or her

learn the necessary skills. The amount of training is tailored to individual needs. As the employee becomes proficient, the training decreases. When skills are mastered, follow-up services are provided. The job coach periodically returns to the work site to make sure the workers with handicaps continue to meet the employer's expectations. If problems develop, the job coach provides one-on-one training until the problem is solved. Follow-up services continue as long as the employee with a disability has the job.

The supported employment initiative requires the coordinated resources of the Division of Vocational Rehabilitation Services, the Division of Developmental Disabilities, and the Division of Special Education. An interagency agreement outlines each agency's responsibilities. The Division of Special Education uses local education agency case managers to identify special education students who have graduated recently or are about to graduate. The case managers work with the families, since family support has been identified as a critical factor for success.

The employee remains the responsibility of the vocational rehabilitation department until the intensive job training phase is completed and the employee has achieved job stability. At that point, client responsibility is transferred to the Division of Developmental Disabilities, which provides long-term support. If an individual does not succeed in employment, representatives from the three state agencies meet to determine the reasons and what can be done to correct the situation in the future.[84]

CONCLUSION

States spend over $7.4 billion annually to care for persons with developmental disabilities. Confronted with tightening budgets, legislators must direct money selectively where it will do the most good. Research and innovative state examples indicate that, given the proper support services, persons with developmental disabilities can hold down jobs, earn salaries, and lead productive lives in the community. At the same time, family support and community programs can produce significant savings through reduced usage of expensive institutional alternatives.

Increasing litigation and pressure from advocacy groups have forced policymakers to address the costs of providing--and not providing--services for persons with disabilities. Today, 60,000 persons with mental retardation who live with their families are waiting for placement in supervised residences and 75,000 more are waiting for employment opportunities, day care, and other services. The failure to provide adequate services reduces the ability of persons with developmental disabilities to become productive, tax-paying citizens. Society pays for inadequate care through increased welfare rolls, inappropriate medical services, and institutionalization. Quality services are expensive, but lack of such services is also costly. This publication is intended to provide legislators with information to help them make informed decisions about systems of care for persons with developmental disabilities in their states.

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GLOSSARY

Case Management--Services that link the individual with appropriate service programs, monitor progress, and provide advocacy services.

Developmental Disability--A severe, disabling condition that arises in infancy or childhood; persists indefinitely; and causes serious problems in language, learning, mobility, and capacity for independent living. Mental retardation, epilepsy, cerebral palsy, multiple sclerosis, and autism are developmental disabilities.

Family Support Services--Services provided to help families care for family members with disabilities in the home. These include financial support, family counseling, and respite care.

Income Support--A direct transfer of cash from the government to the individual. The government determines eligibility and amount of funds to be given to individuals. Cash transfers, such as Supplemental Security Income, Adult Disabled Child benefits, Social Security Disability Insurance, welfare, and food stamps are helpful in assisting individuals in obtaining nonmedical support, such as food and shelter.

Integrated Education--The practice of educating children with handicaps in the same classroom as their nonhandicapped peers.

Medicaid 2176 Waivers--These waivers, authorized under Section 2176 of the Omnibus Budget Reconciliation Act of 1981, allow Medicaid funds to be used for a variety of nonmedical home- and community-based support services for eligible persons.

Respite Care--Short-term care provided to individuals unable to care for themselves in order to provide relief for family or other persons normally providing the care. Respite care services may be provided in the individual's home or in an approved facility, such as a nursing home, foster home, or community residential facility.

Supported Employment--Competitive work in a setting with nondisabled persons for individuals with severe disabilities who require special supervision and assistance to perform the duties of the job.

Title XIX--Medicaid.

Title XX--Social Services; replaced by the Social Services block grant in FY 1982.

Transition Programs--Programs to help young people with handicaps who graduate or exit from public schools find and keep jobs.

ACRONYMS

ADC -- Adult Disabled Child.

AFDC -- Aid to Families with Dependent Children.

COBRA -- Consolidated Omnibus Budget Reconciliation Act.

HCBS -- Home- and Community-Based Services Program, under Medicaid.

HUD -- Department of Housing and Urban Development.

ICF/MR -- Intermediate Care Facility for the Mentally Retarded.

ICFs/MR -- Intermediate Care Facilities for the Mentally Retarded.

IRWE -- Impairment-Related Work Expense.

JTPA -- Job Training Partnership Act.

OBRA -- Omnibus Budget Reconciliation Act.

OSERS -- Office of Special Education and Rehabilitative Services.

PASS -- Plan to Achieve Self-Sufficiency.

SPRANS -- Special Projects of Regional and National Significance.

SSBG -- Social Services block grant; formerly Title XX.

SSDI -- Social Security Disability Insurance.

SSI -- Supplemental Security Income.

SST -- Self-Sufficiency Trust.

TEFRA -- Tax Equity and Fiscal Responsibility Act.

RESOURCES

Administration on Developmental Disabilities
Department of Health and Human Services
200 Independence Avenue, S.W., Room 336-D
Washington, D.C. 20201
(202) 245-2890

The Association for Persons with Severe Handicaps
511 King Street
Alexandria, Virginia 22314
(703) 683-5586

Center on Human Policy
724 Comstock Avenue
Syracuse University
Syracuse, New York 13244
(315) 423-3851

Division of Services for Children with
Special Health Needs
Department of Health and Human Services
Parklawn Building, 5600 Fishers Lane
Rockville, Maryland 20857
(301) 443-2350

Institute on Community Integration
University of Minnesota, 101 Pattee Hall
150 Pillsbury Drive S.E.
Minneapolis, Minnesota 55455
(612) 624-4848

National Association of State Mental
Retardation Program Directors, Inc.
113 Oronoco Street
Alexandria, Virginia 22314
(703) 683-4202

Office of Special Education and
Rehabilitative Services
Department of Education, Switzer Building
330 C Street, S.W.
Washington, D.C. 20202
(202) 732-1427

University Affiliated Program in
Developmental Disabilities
University of Illinois at Chicago
1640 West Roosevelt Road
Chicago, Illinois 60608
(312) 413-1647

American Association on Mental
Retardation
1719 Kalorama Road, N.W.
Washington, D.C. 20009
(202) 387-1968 1 (800) 424-3688

Association for Retarded Citizens
1522 K Street, N.W., Suite 516
Washington, D.C. 20005
(202) 785-3388

The Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091
(703) 620-3660

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, Massachusetts 02140
(617) 876-0426

The National Association of Developmental
Disabilities Councils
1234 Massachusetts Avenue, Suite 103
Washington, D.C. 20005
(202) 347-1234

National Foundation for the Handicapped
340 W. Butterfield Road
Elmhurst, Illinois 60126
(708) 832-9700

United Cerebral Palsy Associations, Inc.
1522 K Street, N.W., Suite 1112
Washington, D.C. 20005
(202) 842-1266 1 (800) 872-5827

National Conference of State Legislatures

William T. Pound, Executive Director

1560 Broadway, Suite 700
Denver, CO 80202-5140
(303) 830-2200 FAX (303) 863-8003

Washington Office
444 North Capitol Street, N.W., Suite 500
Washington, D.C. 20001
202/624-5400

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